

The Core Information Tools for Palliative Care Symptom Management in Patients with Cancer

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ABSTRACT

Purpose: For most patients globally needing palliative-symptom-focused-management care, specialists are not available. Written guidelines are lengthy and impractical for general application when care is needed. Basic tools that address the essential information requirements may help better meet needs of both clinician caregivers and patients.

Methods: Focusing on care for underserved cancer populations, who often received limited treatments, we developed information tool prototypes of 3 types: symptom identification and intensity measurement, key medical problem enumeration, and management algorithms and basic educational materials.

Results: A 15-item symptom identification and intensity assessment instrument and a key medical problem template for cancer were defined and placed on cell phone platforms. Symptom management algorithms based on input from these tools were developed for the most common malignancies in their progressive states, with important recommendation components for each, and specific basic oft-needed patient educational materials.

Conclusion: These information tools provide starting materials for busy clinicians challenged with offering successful palliative care.

Keywords

Symptom reports, Medical problem summaries, Management algorithms, Palliative care tools

Introduction

“The right measure for successful health care isn’t about the maximum possible for a few, but the average for everyone...and the minimum opportunities available to even those with the fewest resources and privileges [1].”

“Imagination at scale is our only recourse [2]”

For most patients globally needing end-of-life symptom-addressing palliative care, specialists are not available or accessible, health systems are weak, and the quality of the interventions received is low (3,4). Primary care clinicians are numerically in short

supply and all clinicians outside of specialists are challenged infrequently by patients needing palliative care, in which then rare circumstances, they are unprepared to immediately offer effective interventions. How can we better address these quality and access challenges which affect high percentages of all human beings at the end of life? We believe that providing specific prototypes/templates for the 3 basic information technology tools needed for impactful palliative care may be useful, for clinicians everywhere but particularly for those in busy low- and middle-income country- (LMICs) circumstances. In this communication we present examples of such tools, explaining their component rationales, and addressing how to obtain and use them. In particular, we suggest that empowering ancillary, allied non-physician health care providers (especially nurses) for use of such tools, offers an efficient and safe means of increasing population coverage for palliative care [5].

We start from a premise that the first and major focus in palliative care needs to be on specific measures to increase and improve patient-provider interactions.

Tool #1: Recognizing patient symptoms and their intensities

The central and primary issue for most patients is symptom management: physical comfort is the sine qua non of successful palliative care. For this core task (of several yes-see Table 1 in reference 5), the key is to provide patients a way with a symptom questionnaire to describe repeatedly their physical discomforts and their intensities. For a long time, the use of symptom questionnaires has been seen by clinicians as a burden, whose time-consuming and impractical applications were poorly justified by any obvious benefits. It has been assumed by high-income country clinicians that they can more efficiently acquire such critical data directly from questioning patients, when this is simply not the case. From multiple perspectives and data sources now, it is clear that use of patient-reported symptom questionnaires improves quality of care and improves multiple patient outcomes [5]. There are a number of well-validated symptom questionnaires, tailored to different clinical situations, with many language translations, whose use however may involve financial costs, and which are not yet available as applications (apps) [6,7]. Our own 15 item, 11 specific symptom, symptom questionnaire is presented here in Table 1 [8,9]. This instrument, the Marquette symptom assessment survey (MarqueSAS), was created particularly with cancer patients in low- and middle-income countries in mind, where symptoms consequent to treatment toxicities are uncommon and therefore are not included (e.g. diarrhea, neuropathy, brain ‘fog’ are omitted). As an application (app) it is available at no cost at the Google Play Store. The name of the app is NAPCare. The MarqueSAS questionnaire apps are available both in Nepali and English (Figure 1). The authors will support creation of this app in other languages, and in text messaging format.

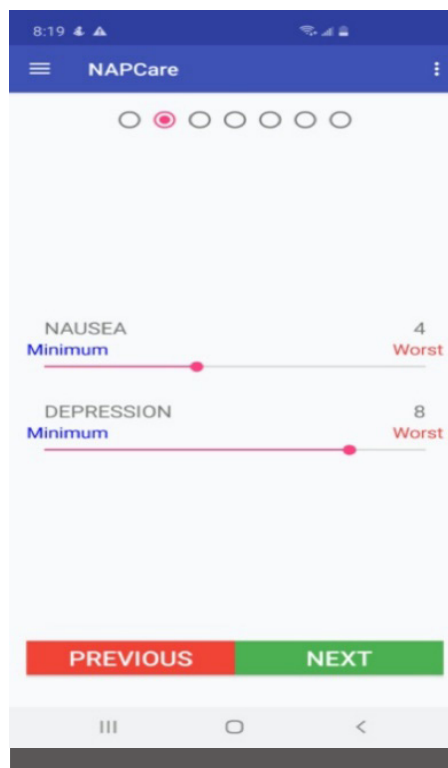


Figure 1: A field from the English version of the MarqueSAS cell phone app used in Nepal. Patients indicate the intensity of their symptom by moving their finger along the Likert scale. Patients who cannot read can also easily use the app.

Tool #2: Medical problems summary

The common palliative care situation for clinicians demands having the key individual patient contextual information in which to interpret the patient symptom information and consider appropriate interventions. Gathering this information is regularly a major barrier to efficient, effective and safe prescription of palliative care interventions because of time. Defining the most common critical kinds of information and devising local solutions for acquiring these data is the second area where a prototype tool can be useful. In Table 2, we offer our suggested medical problem summary template. This template, as for our symptom questionnaire, has been developed for use in populations where cancers are dominantly problems in older individuals with other major non-communicable diseases (cardiovascular, pulmonary, diabetes mellitus), and breast and cervical cancers are the common malignancies in women, and lung and head and neck cancer are the common malignancies in men. The template works well also however with other less frequent cancers because the commonest situations with malignancies leading to end-of-life circumstances, involve metastases compromising function of lung, liver or skeletal organs. What is important about this information tool, is that it provides a starting template for busy clinicians and hospice services to amend as appropriate for their clinical practices. Obtaining this information efficiently can be accomplished by trained health care paraprofessionals, in palliative care centers and locally, which offers a way to increase access to palliative care with minimal direct interaction between health care professionals

| The Marquette Symptom Assessment Survey (MarqueSAS) [8,9] |
|--|
| Nausea ¹ |
| Tiredness ¹ |
| Depression ¹ |
| Anxiety ¹ |
| Drowsiness ¹ |
| Appetite ¹ |
| Well-being ¹ |
| Shortness of breath ¹ |
| Current pain ¹ |
| In last 24 hours: worst level of pain ² |
| lowest level of pain ² |
| usual level of pain ² |
| Constipation |
| Quantity of sleep |
| Quality of sleep |
| ¹ From the Edmonton Symptom Assessment Survey [10]. |
| ² From the Brief Pain Inventory [11]. |

Table 1

and patients. This interaction can be a tele-medical one.

| Medical problems summary |
|--|
| <ul style="list-style-type: none"> • Primary cancer site (menu) • Dominant (or potentially life threatening) loco-regional or distant metastatic site: (menu) • Secondary loco-regional or distant metastatic site: (menu) • Chronic obstructive pulmonary disease Yes/None • Cardiac disease |
| Hypertension: Yes/None |
| Ischemic heart disease: Yes/None |
| Valvular heart disease: Yes/None |
| <ul style="list-style-type: none"> • Cardiomyopathy, type uncertain: Yes/None • Other type: Yes/None • Cerebrovascular disease Yes/None • Diabetes mellitus Yes/None • Any medication with allergic or major adverse reactions |
| Yes Name: |
| None |
| <ul style="list-style-type: none"> • Details of common symptoms which the patient acknowledges |
| Bone pain: Yes/None |
| Major pain site: |
| Recent Development of acute pain with score of 6 or greater: Yes/None |
| Wheezing: Yes/None |
| Productive cough: Yes/None |
| Chest wall/pleural discomfort/pain: Yes / None |
| If yes: Right Side Left Side |
| <ul style="list-style-type: none"> • Patient's major health concern |

Table 2

Tool#3 (and toolbox): Symptom management recommendations algorithm template

The beauty of having information from the two previous tools available for individual patients in need of palliative care is that then any busy clinician can work quickly from a third tool template to define basic potentially impactful palliative care for her patients (Table 3). This template is a clinician basic problem-solving sequence, modified specially for palliative care. We (and others) have developed specific malignancy case type algorithms following from this template, which we would be willing to share, an example of which is offered in Figure 2. As for the clinical experiences in which treatment guidelines lead to improved care, so also use of such algorithms individualizing care can improve palliative care with efficiency.

| Symptom management recommendations algorithm template |
|---|
| <ul style="list-style-type: none"> • This patient's reported major concern is: • Note the major medical problems from this patient's medical summary: • This patient reports allergy or an adverse reaction to: • Suggest targeted physical examination for: • Consider radiological imaging for: • Provide specific medical interventions suggested by symptom, physical examination and imaging findings for treatable conditions: • Review doctors' brief educational item(s) concerning: • Provide patient/significant other written/video educational materials on: • Consider asking patient to submit symptom reports daily • Prescribe specific pharmacological interventions (based on foregoing information and intensity of symptoms): |

Table 3

In tables 4, 5, and 6 we provide examples of the kinds of educational materials which clinicians can have in their "toolboxes" to easily, immediately and efficiently provide their patients (and families).

Common issues for which patient education materials should be available (<https://homepalliativecarenepal.net/guest-site/>)

| |
|---|
| <ul style="list-style-type: none"> • How you doctor can help • Tips for helping with fatigue and tiredness • Ways to help your appetite • Tips to help you sleep better • Managing your pain • Mouth care after treatment • Deep breathing when you are anxious (mini-video) |
|---|

Table 4

Example: Specific recommendations for patients with tiredness score of 5 or > (moderate or greater)

| |
|--|
| <ul style="list-style-type: none"> • Provide tip sheets for "Helping with fatigue and tiredness" and "Tip to help you sleep better" • Stop B blocker medication • Counsel on specific and limited physical activity • Consider low dose prednisone—10mg. daily |
|--|

Table 5

Tips for helping with fatigue and tiredness

| |
|--|
| <p>From your symptom report, you have given a score of 4 or more for the question about tiredness.</p> <p>The most important things to help with this feeling are:</p> <ul style="list-style-type: none"> • To eat as nourishing meals as possible. I will send you some tips about good eating. • To get good rest and sleep at night. I will send you some tips about getting the best sleep. • To conserve your energy during the day by Only doing activities that are absolutely necessary. Plan to do essential activities during the times of the day when you feel strongest. Have other people do thing for you. Try and have the same routine of activities each day. Get and use a wheelchair to go places away from home. • Talk with your family about things that worry you. |
|--|

Table 6

Software system development methodology for the tools

We have used the Agile development method to develop these tools [10]. In such tool development, software development occurs in several cycles. For each cycle, the first step is determining and analyzing the project requirement. Next, the software system is designed with the research team's input and vision. It is expected the team's basic vision for the software tool will develop as content is being selected. Determination of the sequencing of events in the tool and the flow of information is made. Small prototypes of the tool are built and tested by to identify flaws. With feedback from use, software system adjustments are made and the process of analysis, design, coding and building the prototype is repeated. When prototypes are finalized, these are then are ready for pilot study.

Discussion and Conclusion

Our goal with this communication is to provide busy clinicians with information technology tools for palliative care, tools which are not easily accessible otherwise in two ways. First, the availability of symptom questionnaires as free apps for patient use is not widely appreciated. And second, the concepts of a medical summary app and patient symptom management algorithms and prototypes for these for general use have not been openly promoted and demonstrated. We are offering these tools for clinicians to have some "shovel ready" ways to provide palliative care, to facilitate getting more clinicians active in providing such care.

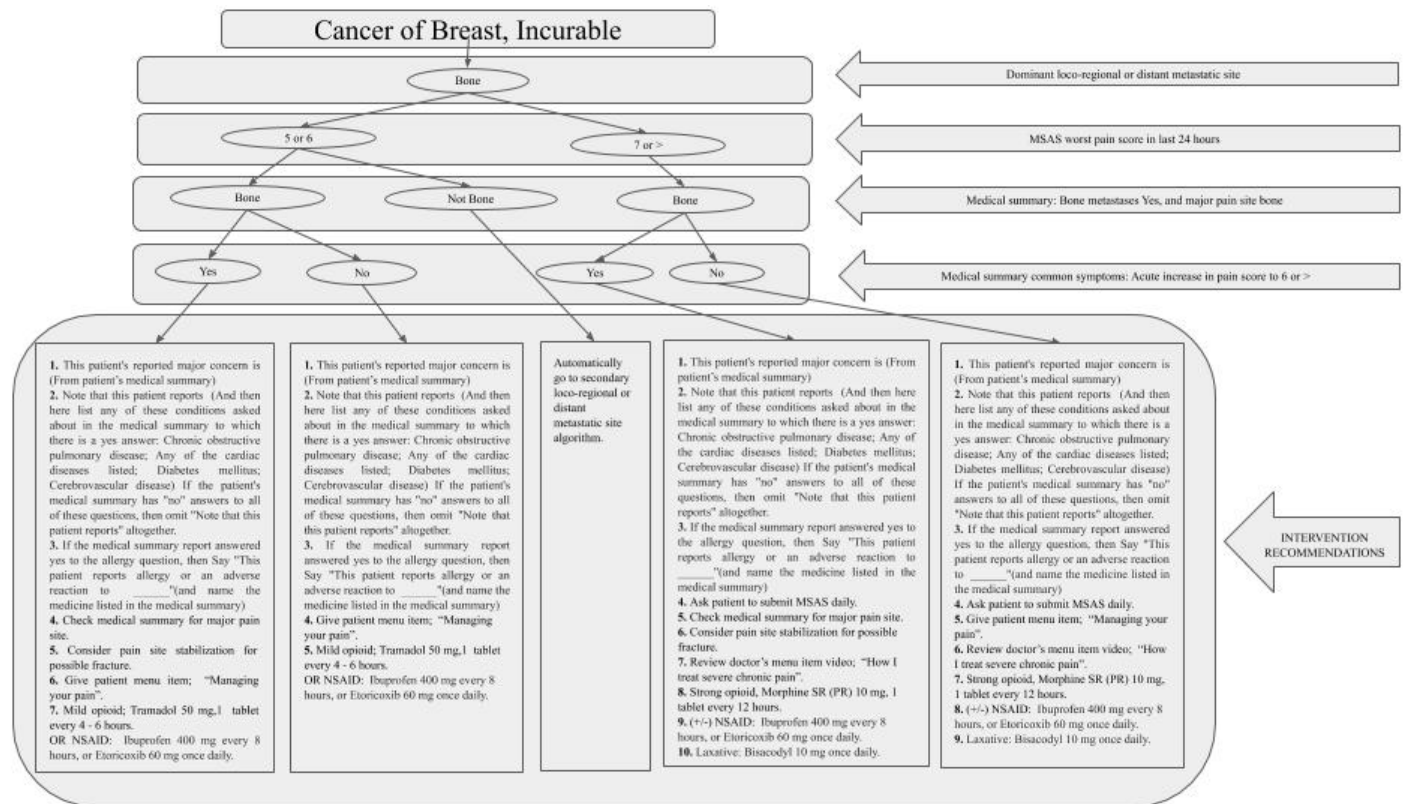


Figure 2: Symptom management recommendations algorithm template for incurable cancer of breast. MSAS= Marquette symptom assessment survey-MarqueSAS (authors' patient symptom questionnaire). NSAID= Nonsteroidal anti-inflammatory drug.

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